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Research paper

At the crossroads: Human rights and the politics of disability and gender in Portugal

Au carrefour : Droits humains et les politiques du handicap et du genre au Portugal

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ABSTRACT

This paper provides an overview of disability policy in Portugal, and advances an analysis of selected law and policy instruments with a focus on issues relevant to the sexual and reproductive rights of women with disabilities. The analysis demonstrates that reforms underway have so far been unable to reverse path dependent trajectories, which erased gender-related concerns from the disability political agenda since its inception. Therefore, issues connected to disabled women's sexual and reproductive rights remain invisible. Given that Portugal has now signed and ratified the CRPD, implementation of the Convention is expected to affect positive change in this important area of rights.

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RÉSUMÉ

Cet article offre un regard sur la politique du handicap au Portugal et avance une analyse des instruments législatifs et politiques, centrée sur les questions relatives aux droits sexuels et reproductifs des femmes handicapées. L'analyse démontre que les réformes en cours ont été incapables de renverser les trajectoires historiques qui avaient effacé les questions liées au genre de l'agenda politique du handicap dès son origine. Aussi, les questions portant sur les droits sexuels et reproductifs des femmes handicapées restent-elles invisibles. Le Portugal ayant maintenant signé et ratifié la Convention sur les Droits des personnes handicapées, on peut attendre de la mise en œuvre de la Convention qu'elle conduise à un changement positif dans cet important domaine des droits.

As in many other countries around the world (Lang, 2009), disability policy and law in Portugal is increasingly framed around the rhetoric of rights. Recent legal instruments and policy papers explicitly articulate a vision of disabled people as subjects of rights, and citizens of equal worth and dignity. This move has culminated in Portugal's signature and ratification of the UN Convention on the Rights of Persons with Disabilities (CRPD), a treaty that has been said to enact a 'paradigm shift' in the way issues of disability are understood and dealt with.

While disability policy is "very broad and diverse" (Waldschmidt, 2009, p. 9) an area where rights have been particularly difficult to secure, particularly for disabled women, is the area of sexual and reproductive health and rights. When progress is achieved in this area, we can also expect improvements in other more traditional areas of disability policy such as employment or social protection. From this point of view, it is relevant to ask whether the recent shift to a rights-based framework in Portuguese disability polity has translated into stronger provisions to protect and advance the sexual and reproductive rights of women with disabilities. This paper seeks to explore this issue.

Drawing from a larger research which specifically examined experiences of mothering among women with disabilities in Portugal and the law and policy context that shapes and constrains their lives, this paper addresses the following questions: How has disability policy emerged and developed in Portugal, and how has gender been taken into account in this process? Is a path-breaking reform underway, notably around the intersecting politics of disability and gender? How do current provisions around sexual and reproductive rights harmonize (or conflict) with international human rights norms?

To answer these questions I review law and policy documents, and assess the most critical gaps, tensions, and contradictions that persist in protecting and promoting the human rights of disabled women, with a focus on their sexual and reproductive rights. In exploring the historical development of disability policy in Portugal, my analysis considers the process of adaptation, translation and resistance to international norms (including norms related to the implementation of human rights) and examines the role of key actors in this process. Path dependence is the concept that supports this investigation and therefore some clarification of this theoretical approach is in need.

The basic assumption behind path dependence theory is that "what happened at an earlier point in time will affect the possible outcomes of a sequence of events occurring at a later point in time" (Sewell, 1996). Thus, explanations of the outcomes of path dependence processes require looking at the system's past (Gartland, 2005), or in other words, history matters in understanding social change (Allen, 2010).

The concept of path dependence was originally developed by economists (David, 1985; Arthur, 1989; North, 1990) studying technology adoption processes and industry evolution, but the approach

is now widely used in the social sciences to explain institutional change. Political scientists and sociologists, in particular, increasingly recognize the importance of exploring outcomes through path dependency, sequence analysis and causal narrativity to theorize not just social change but also social durability and institutional patterns of resistance (Somers, 1998, p. 768–769).

Paul Pierson (2004) conceptualizes path dependence as "dynamic processes involving positive feedback" (p. 20). He argues that politics are a field of social life particularly favourable to path dependent effects due to three characteristics: "the weakness or absence of efficiency-enhancing mechanisms of competition and learning, the shorter term horizons of political actors, and the strong *status quo* associated with the decision rules governing most political institutions" (2004, p. 31). Each of these features intensifies positive feedback processes in politics, making political processes particularly difficult to reverse.

Exploring path dependent sequences entails moving beyond descriptive accounts to examine the circumstances which caused an institution to be started and the process by which institutional patterns reproduce themselves (Mahoney, 2000, p. 512). This invites an analysis of the "power-distributional features of an institution" (Thelen, 2009, p. 490) to identify who is invested in particular institutional arrangements and how that investment is sustained and contested over time.

In this paper, I take insights from path dependence theory to understand the current disability framework in Portugal and the human rights status of disabled women, especially around issues of sexuality and reproduction. The concept of path dependence suggests that existing institutional arrangements may be shaped by previous policies and therefore the significance of their historical context should not be overlooked (Mahoney, 2004). To contextualize my analysis, I begin by offering an historical narrative of disability policy in Portugal that identifies persisting patterns in national disability institutional arrangements. Then I move to an analysis of current reforms to assess the extent to which they represent a path-breaking change. First, however, it is necessary to define the scope, the methods followed, and the data collection instruments that were used in this study.

Methodological issues

This paper is based on a larger research project conducted to explore the daily life experiences of mothers with disabilities in contemporary Portugal, and the broader socio-political context in which they live. The research involved a multimethod approach combining quantitative and qualitative data analyses, drawing from a variety of sources including:

- in-depth interviews with women who are mothering with a disability;
- in-depth interviews with key informants in the Portuguese disability movement;
- secondary quantitative data on people with disabilities in Portugal;
- selected Portuguese law and policy documents focused on disability and/or women's issues.

Findings from the in-depth interviews with mothers with disabilities are reported elsewhere (Pinto, 2010). The legal and policy analysis is the subject of the present paper. Research in this dimension proceeded in two stages. First, the emergence and development of disability policy in Portugal was investigated. Disability-focused legislation, dating back to 1971 (when the first law specifically addressing disability was issued) up to the present date, was gathered and examined. This assessment was guided by three key questions: What conception of disability is embedded in Portuguese legal and policy frameworks? Has it changed over time? And, how has gender been taken into account in disability policy developments?

The second stage involved a human rights-based analysis of selected instruments to address questions concerning the extent to which existing legal and policy frameworks respect, protect, and fulfil the sexual and reproductive rights of women with disabilities in Portugal. This analysis used the norms of international human rights instruments, particularly the CRPD, as standards. A de jure and the facto analyses of key legal and policy documents was conducted using sections of a template developed

in the context of *Disability Rights Promotion International* (DRPI[1]). This assessment tool was designed to monitor disability-related rights in the CRPD and other key human rights instruments (Pinto, in press). It is composed of 44 questions that cover all areas of rights and guide researchers on legal and policy analyses aiming at evaluating the compliance of domestic provisions with international human rights principles and law. In order to answer the questions included in the template, researchers are prompted to develop a thorough review of the laws, policies and practices of the state, attending to the following dimensions:

- identification and description of key legal and policy documents to address each question;
- gap analysis of the laws/policies identified in relation to the standards of the CRPD (or other relevant Conventions) – de jure analysis;
- identification and analysis of other resources (e.g., statistics, national budget and accounts, key informants interviewed, etc) related to the question being addressed–de facto analysis;
- integrated analysis, to assess inconsistencies between laws/policies in paper and in practice and how these impact the human rights situation of persons with disabilities.

In this study, the analysis focused specifically on four human rights and freedoms, usually considered more relevant in connection to issues of sexuality and reproduction for women with disabilities (Centre for Reproductive Rights, 2002): the right to equality and non-discrimination; the right to marry and found a family; the right to sexual and reproductive health; and the right to physical integrity. On the basis of the template's questions which deal with these four rights, 12 contemporary legal and policy documents were identified and subjected to a specific rights-based assessment. In the final section of this paper, findings from this exploration inform a discussion about the scope and significance of disability policy reforms underway in Portugal.

Disability law and policy in Portugal – a historical overview

Path dependence theorists claim that social science research should be historically grounded. In what follows, I trace a brief historical account of disability policy in Portugal, organized around three broad historical periods: the first, which lasts up until the mid-1980s, corresponds to the early years of setting-up a system of social protection; the second, lasting from the mid-1980s to the late-1990s, explores the impact of the integration in the European Union; finally, the third and current one, examines the recent turn to an approach framed by the discourse of human rights.

The Early Years

Along with Spain, Greece, and to some extent Italy, Portugal has been positioned among the cluster of nations which configure the distinctive Southern European welfare regime (Leibfried, 1993; Ferrera, 1996; Silva, 2002). The cluster is characterized by the late development of the welfare state, which to date remains rudimentary and highly fragmented. Families are an important institution in the provision of supports to its members, and the state is only modestly involved in the welfare sector.

The Portuguese welfare state did not really take shape up until the 1974 democratic revolution which removed the authoritative right-wing government that ruled the country for over 40 years (Marques, 1997; Santos, Bento, Gonelha, & Bruto da Costa, 1998; Leiria, 2000; Salvado, 2008). Public initiatives focused on disability at that time were of limited scope. Apart from a few large public institutions, established during the 19th and early 20th century, there were only a handful of charities, founded by families and professionals in the 1950s and the 1960s. Largely perceived as a "personal tragedy", disability remained a private issue, constituting a problem with which individuals and families had to deal on their own. The first law[2] providing a general framework for the rehabilitation of

[1] DRPI is an international collaborative project working to establish a monitoring system to address disability discrimination globally. For more information visit the website at http://www.yorku.ca/drpi/.

[2] Law 6/71 of 8 November

disabled people came to light in the last years of the dictatorship. Clearly entrenched in the medical, individual approach, the law defined as disabled those "who in result of a lesion, deformity or disease, congenital or acquired, are permanently diminished to undertake a professional activity or to carry out daily life activities".

In April 1974, the political regime was turned out through a peaceful revolution led by the military and largely supported by the people. From 1974 to the early 1980s, a series of important changes in the social welfare system took place, enabling the significant enlargement of the social risks covered and an increase in the number of beneficiaries. The new Constitution, adopted in 1976, created the national public health system and enshrined the universal right to social security. Developments in disability policy, nevertheless, were not among the first priorities in the post-revolution expansion of the Portuguese welfare state (Capucha et al., 2004). Initiatives of the civil society preceded state intervention in this domain and took form quite rapidly. One of the manifestations of the emerging culture of civic engagement of the post-revolutionary period was the proliferation of local cooperatives, run by parents of disabled children and professionals, who organized to provide special education services for children with intellectual disabilities. This movement gained national expression in 1985, with the constitution of a federation gathering these local cooperatives which by then had spread across the nation. Gradually, other coalitions of parents, professionals, and/or people with disabilities began to organize to provide social supports to distinct constituencies within the disability community.

This earlier arrangement has had an enduring impact. While the 1976 Constitution included a clause about the "rights and duties of handicapped people", only in 1977 was a national agency created—the National Secretariat of Rehabilitation—to coordinate disability policy at national level. Without a tradition of involvement in the disability area, and lacking the infrastructures on the ground, the state opted to enter into agreement with disability organizations and fund their activities (Capucha et al., 2004), rather than acting as a direct service provider and accommodate people with disabilities in the national education system, the national health system or the post-secondary public institutions. Thus, from very early stages, the state exempted itself from the provision of services to citizens with disabilities (a pattern which only recently it started to revert). This option clearly benefitted state power, but it has had critical consequences for the evolving structure of the Portuguese disability movement. In fact, I argue, it is one of the root causes of its ongoing fragilities and paradoxes, and this fundamentally for two reasons. First, the strategy has fostered an economic dependency of disability organizations on the state, which has weakened and divided the movement; and second, it has also contributed to a lack of clarity as to what are the goals and purposes of the disability movement in Portugal. To date, the Portuguese disability movement remains a highly fragmented social formation lacking a culture of collective action. Since public funding to disability programs has chronically been inadequate, and has even come under increased pressure over the last decade, economic dependency on the state has promoted division among disability organizations, placing them against each other as competitors rather than allies, while fostering an attitude of subservience vis-à-vis the state. The fact that these organizations were burdened with the task of providing very basic services to the population with disabilities, in response to ever pressing needs, had one further consequence—it prevented most of them from allocating time and efforts to advocacy work to address broader disability rights issues, which by then had already started to gain attention internationally. In this context too, intersections of disability and gender were persistently overlooked.

Between 1977 and 1980, the Portuguese state made gradually available a range of disability benefits to families with persons with disabilities, although entitlements were usually low. Parallel to the expansion of the social security system, measures were also introduced in the tax system to specifically benefit people with disabilities, including tax exemptions for the purchase of adapted vehicles[3] or mobility devices, and lower levels of income taxation for people with more severe disabilities (incapacity level of 60% and over), regardless their income level. Public funds were also made available to support education and rehabilitation programs, particularly for children and youngsters with disabilities, although their segregation, notably in the education system, continued to be endorsed[4].

[3] Decree-Law 269/75 of 30 May
[4] Education System Act, Law46/86 of 14 October

A major piece of legislation, providing a general framework for disability policy was not adopted until 1989: the Prevention, Rehabilitation and Integration of People with Disabilities Act[5]. The new bill advanced a definition of disability based on the International Classification of Impairments, Disabilities and Handicaps, adopted by the World Health Organization in 1980: «A person is considered disabled when by lack or anomaly, congenital or acquired, of a psychological, intellectual, physiological or anatomic structure or function likely to produce restrictions in activity, she may be considered in disadvantage for the performance of activities viewed as normal given her age, sex and dominant socio-cultural factors.» In other words, the law ascertained a causal link between the presence of impairments, the inability to perform certain activities, and the experience of social disadvantages. This conceptualization reinforced the traditional, medical model approach to disability. Not surprisingly then, in this and other polity initiatives undertaken during this period the consideration of intersecting effects of disability and gender were absent. Laws and programs largely represented people with disabilities as a monolithic group. And thus, despite all the many achievements that democracy brought for the Portuguese citizenry in general, the issues relevant for disabled women remained neglected.

The impact of the European Union

In 1986, Portugal joined the European Economic Community. Since then, membership in what is now called the European Union (EU) has become an increasingly important force driving the Portuguese state's policies—including in the field of disability—although often with contradictory effects. The political impact of the EU on member-states operates through various mechanisms; notably, the transfer of funds to pursue activities within a programmatic framework strictly defined by the European Commission, the development of instruments and mechanisms of policy benchmarking and coordination among member-states (the so-called Method of Open Coordination), and the adoption of Directives which member-states are required to translate into national law. The three kinds of mechanisms have been successful in affecting change in Portuguese disability policy and law.

As a High Priority nation from 1986 to 2006, Portugal received significant funds from the European Social Fund to support initiatives aimed at promoting equality of opportunities in vocational training and employment for disadvantaged groups, including people with disabilities. The availability of European funds (and required matching national funds) boosted in Portugal the rapid development of the "disability business" (Albrecht, 1992), mostly in the form of vocational training services for people with disabilities. The key players in this new industry continued to be disability organizations. Their numbers, as well as those of beneficiaries, grew quickly and exponentially—from 33 providers offering vocational training to 618 persons with disability in the entire country in 1988 to 65 providers and 3,343 participants just two years later (Veiga, Sousa, Nunes, & Fabela, 2004). This growth continued in the years that followed reinforcing the early patterns of segregate, deficit-based model of service provision, and the economic dependency of these organizations on the state.

Despite the growth, services have continued to be insufficient to address existing needs. In fact, a recent study concluded that only about one third of the population with disabilities in Portugal has ever received any kind of disability-related support (Sousa et al., 2007). The same study further indicated that the majority of those left out have been women. In other words, while the network of disability services has been expanding, the family has never ceased to be an important pillar in the disability framework, especially in the provision of support to their female disabled members. The 2001 census showed that only about 4% of the persons with disabilities in Portugal live in residential facilities of any kind (Gonçalves, 2004). The large majority of them stay with their parents, even after they reach adulthood. The persistent pattern of familialization of disability supports in Portugal is therefore another factor contributing to remove from the political agenda concerns with the sexuality and reproduction of girls and young women with disabilities. In a society of strong catholic tradition, these issues have been dealt with as private matters and often repressed.

The Treaty of Amsterdam signed in 1997, with its new article outlawing discrimination on several grounds including disability and new chapter on employment establishing the European Employment

[5] Law 9/89 of 2 May

Strategy, provided the next impetus for policy development in Portugal. Member-states were required to develop National Action Plans on employment (NAPs), systematically monitored by one another against certain common objectives. NAPs must include measures to improve the vocational training and employment of people with disabilities. In the context of the Lisbon Strategy, similar measures were adopted in 2000 for social policies. The National Action Plans to Fight Social Exclusion and Poverty, which member-states are now required to submit, define national priorities and coordinate the available mechanisms for social intervention at national level; again, they must include, among others, references to measures aimed at reducing the social disadvantages experienced by persons with disabilities. In addition to these so-called soft law mechanisms, in 2000 the Employment Equality Directive prohibiting discrimination in employment and occupation on a number of grounds, including disability[6] was passed. The 15 "old" member-states were given three years to adapt their legislation and translate the Directive into domestic law.

In short, membership in the EU has pushed Portugal toward more progressive disability legislation and stimulated the growth of disability-services provision, albeit with some limitations. EU macro policies (and funding mechanisms) increasingly reflect neoliberal values, emphasizing markets, and thus tending to focus narrowly on employment issues (Waldschmidt, 2009). European strategies on disability are thus riddled with contradictions. Certainly, the social and economic integration of disabled people across Europe is increasingly promoted on human rights grounds, but their participation in a regular working environment is fundamentally viewed as an asset for the Union (Hantrais, 2000). Confronted with high rates of unemployment, which threaten social cohesion and diminish competitiveness in the global economy while placing an added burden on social protection systems, the EU focuses attention on active labour-market measures, deemed to have a positive impact on the beneficiaries as well as on the economy at large. Unsurprisingly, European legislation against disability discrimination so far only exists in the employment sector. Policy areas such as transports, education, access to information, social protection, public health or housing, crucial to create effective inclusion of people with disabilities, have received considerable less attention; to date, the European Commission has not yet responded to the EDF's proposal for a comprehensive disability directive in Europe that would protect disabled people from discrimination at all levels (European Disability Forum, 2007). Similarly, considerations of intersecting effects of disability and gender have not yet gained the disability agenda at European level.

Toward a rights-based approach

In an increasingly globalized world, the last decades have witnessed worldwide the growth of "transnational politics", which are characterized by their global, as opposed to strictly national, dimension and make use of the language of human rights to articulate justice claims (Fraser, 2005). In the disability arena, this broad international shift has been visible since at least the eighties with the celebration of the UN Decade of Disabled Persons 1983-1992 and the publication of several UN instruments including the Standard Rules for the Equalization of Opportunities for People with Disabilities in 1993. The formal establishment of DPI, Disabled Peoples' International as the first world coalition of people with disabilities in 1981, and of the European Disability Forum (EDF) in 1992 to represent the interests of people with disabilities in the European Union, further reinforced the global dimension of disability issues. These international developments stirred in Portugal the adoption of legislation endorsing a perspective of equality and mainstreaming of people with disabilities, notably through the inclusion of children with disabilities in ordinary schools[7] and the removal of architectural barriers in the public built environment[8]. Finally in 2004, it led to the updating of the fundamental law on disability[9]. The new bill presented a redefined conception of disability by focusing on limitations to activity and participation resulting "from the interaction of individual and environmental factors". The act guaranteed

[6] CEU 2000/78/EC of 27 November 2000
[7] Law 319/91 of 23 August
[8] Law 123/97 of 22 May
[9] Law 46/2006 of 28 August

the rights of people with disabilities to employment and vocational training, education and culture, social security, health, housing, sports, and recreation. Disabled people were *encouraged* to participate in policy decision-making processes affecting their lives. In 2004, the Employment Directive was transposed to national legislation through the enactment of a new Labour Code[10]. Two years later in 2006, following a Recommendation of the Council of Europe, Portugal issued its first Plan of Action for the Integration of Persons with Disabilities and Impairments 2006-09 (PAIPDI). In the Plan, disability comes represented for the first time as a "human rights issue". In 2006, as well, a new law prohibiting discrimination on the basis of disability[11] was passed. The bill, which applies to both the public and the private sectors, covers all areas of life including access to goods and services, housing and the built environment, health care, education, and employment. A year later, a National Accessibility Plan[12] (PNPA) was adopted. Recognizing that huge gaps in accessibility persisted in the Portuguese society, the PNPA was introduced as a specific instrument that would help combat the "discrimination and exclusion" experienced by people with disabilities and the elderly.

In short, there is abundant evidence that disability is increasingly being represented as a matter of rights, not welfare, in the national political discourse. Signalling this shift, on 30 March 2007 Portugal was among the states that subscribed to the new Convention on the Rights of Persons with Disabilities on the first day it opened for signature at the headquarters of the UN in New York. The Portuguese parliament ratified the Treaty just two years later, on 31 July 2009. The interesting questions that emerge are then: How should these changes be interpreted? Do they mean we are witnessing a path-breaking reform in disability politics in Portugal?

It might be too early to provide full answers to these important questions but so far the move to a rights-based approach appears to be incomplete. Three limitations are particularly evident. First, the mechanisms of enforcement of new anti-discrimination law and policies are weak or inexistent. The lack of instruments to control the implementation of the norms purported or to sanction abusers have hampered these important tools in achieving their full purpose in practice. Second, the medical model is still prevalent, notably in the eligibility criteria that regulate access to most disability programs and schemes, which continue to rely on medical assessments to determine the applicant's "level of incapacity". This approach denotes an understanding of disability as an individual deficit, rather than as a relationship between individuals with impairments and their social contexts or as a human rights issue, as the policy rhetoric suggests. Finally, recent changes in disability policy and law, despite their emphasis on human rights, advance a very narrow understanding of rights when they fail to bring in a gender perspective, just as gender equality measures fail to mainstream disability. In other words, they fail to ensure rights that are simultaneously gender- and disability-sensitive. This is likely to limit their impact on improving the lives of women with disabilities. Sexual and reproductive rights have been described as the "last frontier" for people with disabilities and an arena where their rights are most often neglected, abused or violated (Kirshbaum and Olkin, 2002). Disability policy in Portugal is undergoing some transformation, at least at the discursive level, with the deployment of the new language of rights but a detailed analysis is needed to assess the effectiveness of the new legal and policy instruments in advancing the sexual and reproductive rights of women with disabilities. I turn to such analysis below.

Monitoring the sexual and reproductive rights of women with disabilities

Looking at sexual and reproductive issues through the lens of human rights opens up the possibility of linking women's well-being (or the lack of it) to the overall social and economic systems that enclose and constrain their lives. Such a perspective acknowledges that women's self-determination and empowerment, including the ability to control sexuality and reproduction, cannot be achieved without transforming oppressive structures that restrain women's ability to make free and informed choices about their lives. It therefore calls on states to take action in sectors that extend beyond health

[10] Law 35/2004 of 29 July
[11] Law 46/2006 of 28 August
[12] Resolution of the Council of Ministers 9/2007 of 17 January

care policies and services, and involve tackling a range of other fundamental rights and freedoms (Freedman, 1999; Petchesky, 2003). To assess the status of reproductive rights of women with disabilities in Portugal, I undertake an analysis of selected legal and policy frameworks that focus on four human rights and freedoms deemed more relevant in relation to women with disabilities sexuality and reproduction (Centre for Reproductive Rights, 2002): the right to equality and non-discrimination; the right to marry and found a family; the right to sexual and reproductive health; and the right to physical integrity. These four distinct rights are well established in international law in treaties and have also been addressed in the CRPD. In what follows, I examine how these rights are protected and promoted in the context of Portuguese legal and policy frameworks and contrast domestic practices with the normative standards of the UN Disability Convention.

Right to equality and non-discrimination

According to the CRPD, the promotion of the right to equality and non-discrimination (article 5) requires that states parties enact legislation prohibiting discrimination on the grounds of disability, modify or abolish law and practice that discriminate against people with disability, and implement the principle of "reasonable accommodation". States are, therefore, obliged to ensure that the modifications and adjustments "not imposing undue burden" that are necessary to grant people with disabilities the enjoyment of rights on an equal basis with others are provided. The Convention also makes clear that special measures aimed at accelerating equality for disabled people or to address specific needs of women and girls are not considered discriminatory.

In Portugal, the right to equality and non-discrimination is entrenched for all citizens in the 1976 Constitution, and has been recently re-enacted in the specific context of disability in two key legal documents—the 2004 Disability Act, and the 2006 Anti-discrimination Law. Both instruments prohibit discrimination on the grounds of disability but the protections they offer come short of what the UN Disability Convention proposes. For instance, the important principle of "reasonable accommodation" is restricted under Portuguese law to situations occurring in the workplace. This means that under existing law, the failure to provide reasonable accommodation in services, facilities, and programmes out of the workplace does not constitute discrimination. Yet "reasonable accommodation" is what disabled women may actually need in order to achieve substantive equality, and enjoy reproductive rights on equal grounds with others.

The fact that Portuguese Anti-discrimination Law limits the principle of "reasonable accommodation" to work-related situations is thus likely to severely hamper the impact of anti-discriminatory provisions on matters relevant to women's sexual and reproductive lives. Moreover, while positive discrimination in the form of specific measures "to accelerate or achieve de facto equality of persons with disabilities" is endorsed in the Portuguese law[13], nowhere in the Portuguese law or policy is it recognized that "women and girls with disabilities are subject to multiple discrimination", and in this sense no special provisions have been taken to ensure that they enjoy all human rights and freedoms on an equal basis with all others. The neglect of a gender-based perspective in disability-related policy and law, as well as the lack of a disability perspective in gender equality frameworks and measures obscure the specific needs and rights of disabled women and girls, including those concerned with their sexual and reproductive lives.

Right to marry and found a family

Also integral to women with disabilities' sexual and reproductive freedoms is the right to marry and found a family (or "respect for home and the family", to keep with the language of the CRPD, article 23). In relation to this right, the Convention emphasizes the importance of free consent of intending spouses, and promotes disabled people's rights to freely and safely control fertility and reproduction, notably through access to family planning education, information, and means. The Treaty also

[13] An Employment Quota System for the Public Sector, for instance, was established in 2001, through Law9/2001 <fn0070>of 3 February

highlights the rights of parents with disabilities to appropriate assistance so to enable them to fulfil parenting tasks; furthermore the Treaty imposes legal guarantees to ensure that families are not separated on the basis of either the child's or the parents' disability.

In the Portuguese context, legal statutes that frame "respect for home and the family" reflect the hybridization that currently marks the changing terrain of disability policy, where old and new forms of protection often intersect and collide. For instance, the Portuguese Disability Act endorses the principle of autonomy recognizing that persons with disabilities have the right to self-determination on all matters concerning their lives. Presumably, rights related to marriage and family including free consent of spouses are taken into account in this formulation. This provision, however, sharply contrasts with the clauses of the Portuguese Civil Code which regulate both the regime of interdiction and the relationship of marriage. In its article 138, the code identifies those who may be subject to legal processes of interdiction (and thus prevented from exercising their rights) as, "individuals who are unable to govern themselves and their assets, due to psychiatric anomaly, blind-deafness or blindness". The statute further establishes that individuals who have been determined "interdict" by the courts on the basis of "psychiatric anomaly" are prevented from celebrating marriage (art. 1602). Thus, the Portuguese Civil Code is overtly discriminatory towards people with disabilities in two senses. First, it sets apart some conditions of impairment and assumes them as direct causes of inability. Most importantly, in its stipulations, the code uses derogatory language, offensive to the human rights and dignity of disabled people. In both senses, the tension between two distinct ways of understanding and dealing with disability are more than evident in these two contrasting pieces—a socio-political approach based on the recognition of the equal rights and freedoms of people with disabilities found in the Disability Act, and the traditional, restrictive approach, informed by a biomedical conception of disability, maintained in the Civil Code. A genuine human rights perspective requires the Portuguese state to eliminate these tensions by abolishing or changing law and regulations that are discriminatory to people with disabilities.

Right to sexual and reproductive health

In other instances, however, contradictions are more subtle. Such is the case of law and policy around sexual and reproductive choice and health. The right to sexual and reproductive health is addressed in the Convention under article 25, which grants the right to the enjoyment of the highest attainable standard of health. In this sense, governments are urged to take the necessary measures to "provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health". In particular, state parties must require health professionals to provide care "on the basis of full and informed consent", by inter alia raising their awareness about "the human rights, dignity, autonomy and needs of persons with disability". Rights to access family planning and age-appropriate information and education, as well as the right to control one's fertility and reproduction are further recognized in article 23, which also entails governments' obligations to provide the means necessary to exercise these rights.

Rights to control fertility and reproduction are framed by the Portuguese state as human rights issues (Canço, 2007). Since 1984, free access to family planning and sexual education is granted to all, aimed at ensuring a healthy and satisfying sexual and reproductive life. Information, knowledge, and the means necessary to control fertility are made available through community health centres and public hospitals. In a nation of strong Catholic tradition, abortion rights have been more difficult to achieve, but these too have gradually been introduced. The most recent development happened just in 2007, when following a national referendum a law was issued de-criminalizing abortion within the first 10 weeks of pregnancy[14]. In theory, women with disabilities are entitled to all these rights, but in practice they face numerous obstacles, and would require special measures and accommodations in order to effectively enjoy reproductive freedoms. For instance, information and education on sexual and reproductive health ought to be available in multiple formats to accommodate disabled women's

[14] Law 16/2007 of 17 April

diverse levels of needs and abilities. Professionals ought to be adequately trained to understand intersections of disability and sexual and reproductive health, to respect the human rights and dignity of women with disabilities, and to provide them sensitive care and support. Given the increased marginalization and isolation of women with disabilities, additional efforts would be necessary to reach this population with information and education campaigns, and warrant them access to reproductive health services. There is, furthermore, the need to ensure that facilities where sexual and reproductive health programmes and services are offered are accessible to women with a range of physical impairments. Unfortunately, Portugal is far from offering any of these guarantees. Yet, in the text of the decrees that rule matters of reproductive health in the state or that articulate rights to health without discrimination for people with disabilities, there is no acknowledgment of these gaps, and even less an explicit intention to fill them in the near future. Key policy instruments are equally mute on the subject—neither the III National Plan for Equality, Citizenship and Gender, which traces government policy on women's issues and gender equality in general, nor the PAIPDI, the document that spells out national goals and actions in the area of disability, have anything to say about the reproductive rights of disabled women or the task ahead the government in order to ensure the effective exercise of these rights by this group of women. This despite the government's stated commitment to promote and protect the human rights of people with disabilities, and its strong support for the principle of non-discrimination, expressed in major legal and policy documents, including the PAIPDI.

Furthermore, special measures to assist mothers (and fathers) with disabilities with their parenting tasks, as it is envisaged in the Convention, are nowhere to be found. Although the Portuguese state places a high value in the family (see, for instance article 67 of the Constitution), and although the Labour Code grants working parents several protections including maternity and paternity leaves, and sick-child parental leaves (which may be even extended if the child has a disability), no special entitlements exist for workers who are parenting with a disability. Similarly, while in general the right of all children to not be separated from their parents is protected in the Constitution (art. 36), there is no guarantee that the disability of the child, or that of one or both of the parents cannot be invoked to justify the removal of the child from their natural family. And although the Portuguese Disability Act contains a clause on "support to family", it is too vaguely articulated and thus seems insufficient to stimulate specific action on this area.

The right to physical integrity

The right to physical integrity encompasses two important sexual and reproductive freedoms: the right to make decisions concerning one's health and body, and the right to be free from sexual abuse and exploitation (Centre for Reproductive Rights, 2002). The CRPD specifically guarantees these freedoms for people with disabilities under articles 25 (health) and 17 (protection from exploitation, violence and abuse) respectively. In Portugal, the right to self-determination is generally protected for people with disabilities under the Disability Act, but this principle has had little or no resonance in matters related to women's sexuality and reproduction. Traditional practices and the system of interdiction and guardianship endorsed by the current Civil Code (as discussed earlier) allow in practice family members to make health decisions on behalf of people disabilities and often without their consent, including decisions about medical interventions (such as hysterectomies and other forms of forced sterilization).

Freedom from sexual abuse has also not been sufficiently looked after for women with disabilities. Research has shown that women with disabilities are at increased risk for sexual abuse due to their isolation, economic and physical dependency, and lack of education about appropriate and inappropriate sexuality (Nosek, Foley, Hughes & Howland, 2001). However, the national framework to fight gender-based violence, notably the III Plan on Domestic Violence (2007-2010)[15] overlooks this amplified vulnerability, actively constructing the category of women as non-disabled and the category of disabled women as a-sexual. In short, the right to physical integrity of women with disabilities

[15] Resolution of the Council of Ministers 83/2007 of 22 June

seems inadequately protected in current institutional frameworks around disability and gender in Portugal.

Conclusion – path-breaking or path dependence? Disability policy at the crossroads

The empirical data presented above indicates a pattern of persisting invisibility of matters concerning the sexual and reproductive rights and freedoms of disabled women in Portuguese policy and law, as well as the lack of accommodations and specific supports to effectively ensure the respect for their sexual and reproductive human rights. This invisibility signals a deep-rooted challenge—it indicates the government and society's persisting inability to imagine sexual and reproductive roles for women with disabilities. This suggests that images of dependency, invalidity, and asexuality remain associated with disabled women's lives. Disabled women continue to be socially construed in accordance to a medical model, viewed as essentially different "others", whose disabilities strip them of womanhood, and thus forego the measures and approaches generally deemed appropriate to deal with women's issues. Under these conditions, inequalities for women with disabilities are likely to continue.

The ongoing invisibility of matters related to the sexual and reproductive rights of women with disabilities, in spite of the recent turn to a rights approach in the legal and policy documents, suggests that Portugal has not reached a path-breaking point in disability policy after all. Beyond the seeming changes there is much continuity in the institutional responses to disability, and in particular, an unrelenting disregard for intersections of disability and gender. The several factors, with historical roots, that account for this situation have been highlighted throughout this paper. They include early decisions about the role of the state and that of disability organizations and the dynamics of their relationships; the familialization of disability supports and the protective stance of families particularly vis-a-vis their disabled female members; and the persistence of approaches informed by the medical model, which tend to obscure the disparities within the group of persons with disabilities, notably those gender-related. All these factors, which date back in time to the post-revolutionary period when disability policy began to take shape in Portugal, have had an enduring effect in erasing from the political agenda attention to the intersecting effects of disability and gender, particularly in their sexual and reproductive health and rights dimensions. Current reforms have still been unable to reverse these path-dependent trajectories.

Yet simultaneously, there is a real creative and transformative power in the new rights-based rhetoric framing disability in Portugal. Its potential, I argue, will greatly depend on the ability of the disability movement to build on this momentum and use human rights, and especially the CRPD, as a tool to push for disability and gender justice in social, and not just discursive, practices. Now that Portugal has ratified the CRPD, the state is legally bound to new obligations—including the duty to take appropriate measures to fight the multiple discrimination facing girls and women with disabilities. Disability organizations have had an historical role in addressing disability issues in Portugal. The implementation of the CRPD can once again provide the disability movement an invaluable instrument to affect positive change in this important area of rights.

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